

DOCUMENT RESUME

ED 245 492

EC 162 852

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TITLE "Give Me a Break": A Parent/Professional Success Story. Respite Care in the 80's.
PUB DATE 26 Apr 84
NOTE 18p.; Paper presented at the Annual Convention of the Council for Exceptional Children (62nd, Washington, DC, April 23-27, 1984).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Developmental Disabilities; Program Descriptions; Program Design; *Respite Care
IDENTIFIERS *Temporary Care Services

ABSTRACT

The paper describes the Temporary Care Services program in Massachusetts which provides in-home respite care to families with developmentally delayed children. Events which led to the program's development are reviewed. Respite care is offered in six areas: emergencies, scheduled routine events, social activities, family life, child care for working parents, and "overnights." Respite workers (many of whom are students) are trained in such areas as behavior management, home safety, and self-help skills. A training manual accompanies the training program for respite workers. Fund raising efforts are mentioned, and experiences with other agencies are related. (SW)

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"GIVE ME A BREAK": A PARENT/PROFESSIONAL SUCCESS STORY

RESPITE CARE IN THE
1803

Presented at the 62nd Annual Convention
of the

Council for Exceptional Children

April 26, 1984

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CEC PRESENTATION

GIVE ME A BREAK: A PARENT/PROFESSIONAL SUCCESS STORY: RESPITE CARE IN THE 80'S

Overview

We are extremely proud to be presenting the Temporary Care Services program to the CEO Convention. What we have done in Massachusetts we believe can be done in other communities. We would like to ease the way a bit for other groups wishing to set up a respite care program. We know some of the pitfalls, pratfalls, and disasters that can occur. That's one of the reasons we are here. But we're also here to boast a bit. We began as a group of people with a very good idea and no firm sense of how to go about making it a reality. But now - for four years, in fact - it has been a reality.

We've learned a lot along the way. We now have a state contract, foundations are getting more responsive, the community has begun to notice we're around. We've even begun to dream a little about expanding the types of services we wish to offer. None of it has come easily!

Today we'd like to tell you how we got here, how our program is designed and why we designed it the way we did. We'll tell you how we've developed inter-agency cooperation, strategies that have been so necessary to our continued existence. And we'll explain how we go about fundraising and generating community awareness.

Throughout, it is important that you keep in mind how very involved parents are in Temporary Care Services. They were here when we began. They are listened to thoughtfully and with respect by the other Board members. We believe that families know more about what they need than an army of agencies. They know more about the dynamics of life with a disabled child and that knowledge has molded our philosophy. Before we tell you about TCS, then, we want to tell you just what that philosophy entails.

Respite care is a response to the need that all people have to tend to their own concerns and be free to pursue their dreams. Because disabled children require such constant care - such continual supervision - their parents and siblings are under extreme stress much of the time. They are exhausted. They feel battered and imprisoned. As time goes by their sense of proportion shifts and they begin to acquire a siege mentality. Their imagination can disintegrate, making it more difficult to care for able and disabled children alike. Under these circumstances it is no wonder that families shatter. Divorce, institutionalization, and child abuse are some of the results of stress unrelieved for weeks, months - sometimes years - at a time.

By providing families with a chance to "get away" to take a break and tend to themselves - we hope to reduce that stress and make it more comfortable for them to cope with the strains of life. In order to do that effectively we must be able to offer them flexible respite; available when they need it and want it - with enough hours to make it meaningful. So that's what we do - and it works. It is not enough - not yet - but it is the kind of start that holds promise.

Anyone else considering a respite service should make note of one salient fact. With in-home respite services you can begin small - and cheap. You can get by with a small office, someone to direct the staff, and some respite workers. You don't need a site and building permits. You don't have to hold community meetings and explain to the neighbors that these kids are not drug abusers and they won't entice the sons and daughters in the neighborhood into lives of crime. You don't have to try to find funding to meet the expense of altering a facility to accommodate both the disabilities of the children and the concerns of the building inspector.

You can make the lives of parents tolerable and give them the opportunity to become part of the life of the community they inhabit. That's quite a lot.

History

The following brief history of the development of Temporary Care Services makes clear the cooperation of parents, providers, and local social service agencies in the Cambridge/Somerville area.

In 1977, a teacher of multiply handicapped children and a group of parents began the annual search for an appropriate summer camp for their children for two reasons: so that the children would have a fun, healthful, and relaxing two weeks, and so the parents would have a brief respite from the job they did for 50 weeks a year. The parents felt that, in the United States at least, most if not all contemporary workers deserve at least a two-week vacation annually.

Few if any camps would accept these students, due to the nature of their multiple handicaps. The quality of some camps was in question, and one or two which accepted children with multiple handicaps were at least a six-hour drive away. This process of working closely with the parents and trying to find them some relief was a real "eye-opener." It underscored the day-to-day difficulty of handling their disabled children. Although this group of people was successful in finding camps for some youngsters, other parents were understandably reluctant to send their children away for two or three whole weeks. What they wanted was relief, a change of pace, a change of routine. In other words, they wanted a brief respite from their responsibilities.

During the summer of 1977, after contacting the local Office for Children in the Cambridge/Somerville area and discussing with them the lack of respite services, an initial meeting was organized with representatives of the local agencies which served families, children with disabilities, and the mental retardation office. The purpose of this first meeting was simple: to establish a vehicle for talking about respite care. At this meeting the Respite Care Committee of the Office for Children was born. Its mandate was to determine what respite care services were available to parents in our area, to determine what needs existed

for respite services, and to identify possible funding sources. The original goal was to interest one of the member agencies in providing the respite which was so desperately needed.

Suffice it to say, no agency was interested in doing this. Some were already providing some limited respite care. However, this respite was most often residential, not in the homes of the families, and was limited by several factors such as geography, types of disability, parents' ability to pay, and age. Some also required parents to participate in training programs; some were also only available during the week day from 9 - 5. Needless to say, these programs only served a small fraction of the actual population, and did not serve children and young adults with seriously handicapping conditions, with behavior or medical problems, or teenagers.

For three years the Respite Care Committee met, planned, participated in conferences, and publicized the need. The Respite Care Committee met with parents of special needs youngsters and agency personnel. Members of the Respite Care Committee included: special education teachers, representatives from the Office for Children, a Cambridge School Department special education administrator, parents, and agency personnel from the Department of Social Services, a couple of private agencies, and occasionally but not often, a representative from the local mental retardation agency. A subcommittee conducted a needs assessment of over 200 families with special needs children in the Cambridge/Somerville area, and determined that their first priority was a respite service in their own homes, and secondly a summer residential program for two weeks at a time.

At the end of two and a half years of often frustrating meetings, it became clear that no established agency wanted to take on respite care, and that a local community group could not force them to do so. After contacting a local lawyer who volunteered his time, and with the continued assistance of the staff at the Cambridge/Somerville Office for Children, in December of 1980 Temporary Care Services, Inc. was established as a nonprofit corporation. A special needs teacher

was president, a nurse who had worked for many years at a facility for the mentally retarded was vice-president, and a parent of special needs children became treasurer. The first board of directors included several parents of handicapped children, a couple of local lawyers, special needs teachers, additional interested friends and citizens.

As a nonprofit corporation Temporary Care Services, Inc. could now apply for funding from state agencies, private foundations, and any other source which might be of assistance. As a nonprofit corporation, the first task was, therefore, to write a proposal which would get us some funding. The second task was to clearly define the type of program needed. These two tasks were accomplished over a period of years. The initial proposal was written and revised many times. Board members have been refining the program itself since incorporation, making the respite program as accessible to and flexible for parents as possible.

A couple of points are very important to consider. From the start, Temporary Care Services, Inc. made a commitment to involving parents of special needs children and to developing a program which they wanted and helped to design. This was not as easy as it sounds. Without respite it was very hard for parents to get out to meetings. Meetings were held at the convenience of parents, and rides were often provided for those who didn't drive. Board members tried to avoid professional jargon, and tried hard to really listen to the parents. Staff learned by doing, made phone calls, sent one of the lawyer Board members into the State House to find out what to do with the forms. Initial efforts were not flawless. Since every Board member had a full-time job, including the parents whose job is more than full-time, everything seemed to take a long time. Proposals were written and rejected. Proposals were sent to the wrong foundations. Without dwelling on errors, every mistake there was to make was tried, but the program survived, operated, and involved parents every step of the way.

Program Description

Temporary Care Services will provide in-home respite care to any family in Cambridge or Somerville, Massachusetts, with developmentally delayed children. We have purposely defined our service population as developmentally delayed, so that as many of the families who need the program can avail themselves of it. These children may be retarded, brain-damaged, or have a variety of developmental disorders that interfere with normal functioning. Whatever the diagnosis, these are children who require specialized training on the part of caretakers. Any child who cannot safely be left with the more standard babysitters qualifies. The Temporary Care Services program is available for these children from birth through age 22.

We offer up to 30 hours of respite care every month to each family. They may use as many or as few of those hours - even none at all - as they wish, in any way they desire, when they need them. Although some families take the full 30 hours in a structured, scheduled way each month, most vary their usage, taking perhaps 6 hours in one month and 25 hours the next. Our workers are assigned to families so that children are assured of having the same worker each time. At least one backup worker is also assigned in case the primary worker is unavailable. Temporary Care Services families are assured of having respite care in emergencies as well.

Families use respite care in a variety of ways confirming our belief that the best kind of in-home respite care is extremely flexible. Indeed, meeting the individual needs of many different families can only be achieved with as few restrictions as possible. The diversity of use is striking. Service evaluations have consistently shown that there are six general categories of respite care use:

- :: Emergencies
- :: Scheduled Routine Events
- :: Social Activities
- :: Family Life
- :: Child Care for Working Parents
- :: Overnights

Emergencies : There have been at least 35 calls for emergency respite care since May, 1982. These are situations which arise suddenly creating an urgent need for respite care.

A medical emergency in one family, for example, arose in the early morning when the mother had to be rushed to the hospital. The father called TCS at 6:30 A.M. requesting a respite worker for their 8 year old son. By 7:30 the respite worker was in the home making breakfast for the child while the father was able to join his wife at the hospital.

A less dramatic, but no less urgent, emergency arose for the single parent of a boy with Down's Syndrome. She fell ill with flu and was unable to care for her son over the weekend. Two TCS respite workers worked in relays covering the weekend: making meals, dressing the child, bathing him, and entertaining him so that his mother could rest in bed.

Scheduled Routine Events: Attending to the more mundane aspects of life, or attending a regularly scheduled activity is complicated for parents with disabled children. Many families, therefore, regularly use respite care for such occasions as grocery shopping, doctor's appointments, school activities, errands, or sports events. A few parents have taken advantage of respite care to return to school.

One of our single parents regularly participates in sailing races on Boston Harbor during the summer months. She uses respite care for her disabled son to allow her to do so.

Social Activities: Being able to enjoy the company of friends, attend cultural events, or simply getting out for a few hours together is frequently impossible for parents of disabled children. One parent who uses TCS respite care spoke of not having any social life she and her husband could enjoy until TCS provided them with respite care. She expressed her excitement about going to a movie together for the first time in years.

Another mother used two hours during the day to go to the hairdresser's which she highlighted as a definite social event.

Family Life: Many families arrange to have respite workers stay with their handicapped youngsters while they spend time with the other children in the family. Others bring the respite worker with them on family outings so that the disabled child can participate in family events without being the focus of all the parental attention.

One father shared his frustration at not being able to devote enough time to his older child because of the amount of care, attention, and discipline his disabled daughter required. Respite care has provided a way for him to share time with his son that was impossible before.

Child Care for Working Parents: The necessity of working outside the home has made it imperative for many families to find child care before school, after school, into the evening hours, and during school vacations.

One single mother reentered the work force after several years of raising her child with help from Aid to Families with Dependent Children (AFDC). Since she did not return from work until 5:30 and her son was out of school at 2:30, TCS coordinated services with another agency and together they provided sufficient respite care and after school programming during the crucial hours.

Overnights: Parents occasionally wish to go away together, either to refresh their relationship or to visit family or friends. Respite care provided overnight can make these short excursions possible.

A couple with a disabled daughter and two disabled sons enjoyed their first weekend away from the total care of their children in fifteen years because they were able to arrange for a team of respite workers to provide care while they were gone.

Although most initial requests for respite come from the family directly, we regularly receive referrals from social service agencies. In order to make the

intake procedure as easy and unpressured as possible, we have developed a simple but thorough process. The program director talks with the family on the phone to assess their respite needs. A referral form is completed which includes specific client information and a brief overview of the child - his skills, behaviors, medical history, habits, etc. Once the program director has determined that Temporary Care Services is the appropriate agency, a home visit is made to orient the family to TCS and gather more extensive information. The program director then matches the needs and capacities of the child with the appropriate respite worker(s). If we are unable to provide service, for any reason, we make every effort to refer families to the appropriate agencies or programs.

Where do our respite workers come from? Many are students in special education courses at local colleges and universities. Some are teachers of special needs youngsters who wish to develop a greater understanding of the children with whom they work. Some are siblings of handicapped youngsters who carry with them a particular understanding of the dynamics of life with disabled children. A few responded to our ads with no background with disabled people at all.

We put all of them through our own screening and training program. We require Red Cross certification, CPR certification, and completion of our 20 hour training program. In addition, once they are working as respite workers, they are regularly supervised by the program director. They are, therefore, fully qualified to care for a wide range of disabled children, including (but not limited to) the retarded, those with speech and language impairments, physical disabilities, neurological involvements, and those with multiple handicaps. This last group has been singularly underserved in the past and was, in fact, one of the groups of children that inspired the founding of TCS.

Our workers are trained in behavior management, communication skills (including sign language), normalization, self-help skills, play and recreation, home safety and childproofing, and medical and emergency procedures. Workers are

given an orientation to TCS, its policies, procedures, and philosophy. In addition, workers receive specific training for each child assigned to them, not only from the program director, but from the families as well during the initial visit.

To ensure that families' changing needs are met, we conduct extensive consultation with them at regular intervals. The parents' expectations are, therefore, defined and the workers have a good idea, not only of the problems they might encounter but of developing skills and initiatives of the children.

TCS has created a training manual that we wrote to accompany the training program. The Respite Care Manual includes sections on the various techniques which can be employed in caring for these children and emergency procedures, but goes further. Articles written by parents detailing their lives and complications of living with a disabled child gives workers insight into the dynamics of their lives. A section on quotes from other respite workers helps new workers to understand the scope of the care they are being trained to provide and share experiences others have had before them. To enlarge upon the Red Cross course, The Respite Care Manual includes articles written by medical personnel dealing more extensively with specific situations and disorders. The Respite Care Manual serves as a handy reference and training resource for the respite workers, each of whom receives a copy.

During respite sessions workers seek to provide a safe, enriching, and positive experience for the child. They engage her in enjoyable activities and participate completely in all aspects of her care.

The specifics of a respite session are as varied as the population we serve. The respite workers' duties may range from going on a field trip to caring for a sick child; from teaching a child to drink from a cup to playing a rousing game of softball; from tucking a toddler into bed to dealing with a tantruming, self-abusive child.

Often respite workers are able to teach a child a new skill or provide the family with help in dealing with a behavior problem. One single mother who

worked on an early shift at a hospital has a TCS worker come in the mornings. She and the worker together created a dressing program to teach the child to dress himself. The worker was able to reinforce this program each morning. Within several weeks the boy was able to dress independently.

Fundraising

Temporary Care Services started in 1977 with a few interested professionals, two teachers, two parents, and no money. Our finances have improved slightly since then, but we continue to prove that a lot can be done with modest resources.

Our nonprofit agency has grown considerably in 7 years. Staff includes 18 members of the board of directors, 1 program supervisor, and 10 respite care workers providing in-home relief to more than 30 families for less than \$30,000 per year. Funding for TCS has come in large, medium, and small donations from a variety of sources. Funding has come from such varied agencies as private foundations, the Department of Social Services, the Bureau of Developmental Disabilities, as well as contributions from friends and relatives. Also, a host of fund raising activities have been sponsored by parents and staff at TCS. To a lesser extent, money is collected from the families served on a sliding fee-for-services scale. Since most families do not pay for the services, collection of fees represents less than one per cent of annual income.

During the first year of operation TCS was very fortunate to receive a \$14,000 start-up grant from the Hyams Foundation. This award has been the highest single grant to date and allowed us to recruit, hire, train, and salary the original team of respite care workers. Through this grant we were also able to start work on a training manual for respite workers, disseminate information about our program throughout the community and attract interest in our program from other foundations.

Subsequent funding has consisted of several smaller grants, and a steady stream of creative, energetic fundraising events. We have organized dinners, picnics, dances, boat rides, car washes, bake sales, and raffles. Soon we will

offer an auction and a fashion show. For those unable to attend our functions we have set up a direct mail appeal whereby hundreds of letters were sent to friends, relatives, politicians, community leaders, and TV personalities with good results. Last year we collected more than \$500 representing a 10 per cent return.

Recent contributions have included several \$5 and \$10 checks from parents of children with special needs as well as children without special needs, \$400 from the office of the Speaker of the House of Representatives, and \$2,500 from our good friend "Anonymous." An interesting idea emerged this past Christmas when Memorial Church at Harvard University decided to sing for TCS and donated the proceeds from three caroling services to the program. In January they generously sent us a check for \$2,616.

Total fundraising for 1983/84 yielded \$14,816. Individual amounts included \$10,116 in foundation grants, \$4,000 from a dance, a dinner, and a raffle; and \$700 in miscellaneous gifts. An additional \$19,000 from the Department of Social Services was collected when we provided respite care to clients of that state agency. The \$33,816 total income to the program more than adequately covered program expenses which totaled \$29,000.

It is quite gratifying to report that despite our shoe string appearance (two years ago we had to take up a collection to pay an annual insurance bill of \$1,200), we have succeeded in providing 30 families with 30 hours each month of well-planned, qualitative in-home respite care.

Interagency Cooperation

One of the most frustrating circumstances any group endeavoring to create a service program is likely to encounter is getting other agencies to cooperate. However much the agendas of the various service providers in a given area may not overlap, there is always a tendency to see a new group or organization as a threat to the existing structure. Interagency animosity can make the struggle to establish a program extremely complicated - even when that program in no way duplicates existing services. Having been through it (complete with false

starts, blind alleys, classic runarounds, and outright resistance) we feel we have information to share that may be helpful for other groups attempting to set up a respite care program in their community.

There is no substitute for personal contact. Knowing with whom you are dealing, what their assessment is of the need and how to meet it is an important beginning. From the start TCS involved agencies both local and statewide in planning. It seemed a good idea at the time - and it lulled us into thinking we had covered those areas of potential resistance by including everyone who might offer it. Looking back, it still seems a good idea - but naive. Enthusiasm for an idea is one thing. Who couldn't be enthusiastic about providing families of handicapped children with respite care? But translating that enthusiasm into action for the benefit of a group of people who wish to set up a private agency is another.

There was no existing in-home respite care service in Cambridge and Somerville when we began. As we noted earlier there were a couple of respite facilities with extremely limited space, few available hours, requirements as to the type of disability and/or the age of the child, and that was it. None of the existing agencies had any plans to organize an in-home, comprehensive, flexible service. The coast, as they say, was clear. And there we were, ready to fill the gap, overflowing with the ignorant confidence of amateurs, sure of our purpose, and equally sure we had the support of everyone else. We didn't - though the idea of in-home respite care did.

At a public meeting to discuss respite care our presentation was greeted with resistance coupled with a bit of hostility. It wasn't needed, we were told. It was ill-conceived, poorly planned, and unnecessary. All of which did uncomfortable things to our egos - to say nothing of what it did for our confidence in assessing support. We briefly went underground, nursing our wounds and continuing our planning, but with slightly dimmed hopes.

Now - assessing the first years of planning - it is obvious to us (more experienced and wiser as we now are) that there really was no reason why every social service agency in the area ought to throw unqualified support behind a group of parents, teachers, and other citizens who had never organized or run a respite agency. Knowing what was necessary - and the parents knew that in spades - didn't make us experts on providing it.

There followed a series of crises, unrelated to respite care, in social services that had to do largely with the disappearance of money to provide services. In Massachusetts, a law, Proposition 2½, limiting real estate taxes put local school departments in a bind resulting in proposals to limit special services and after-school recreation programs. On the state level, reorganization substituted for progress and further endangered services. On the national level federal grants began to dry up. Besides trying to get TCS flying, many of the Board members began to fight for continued services or the reestablishment of services that had been cut in the first flurry of budget slashing.

In the process we learned a valuable lesson - people help people who help them. Without quite realizing it we had made contacts and established our willingness to be part of the entire network. We amateurs slowly emerged as experts and our new-found status soon developed into a perception that we were "professionals."

A summer of working with several other agencies to form after-school programs for disabled children led, eventually, to the creation of a local group of agencies that provide respite services. Originally planned as a vehicle for determining where gaps existed, it has grown into a force for the development of programs.

Four years later we had become the most active and well respected respite agency in the area. It only happened because we engaged with the other agencies, lent them our energy when we had little expertise, shared our expertise as it developed, and met their expectations in providing service.

What we did by happenstance - we really didn't know we were developing interagency relations - reflection suggests can be done with purpose.

- Learn about all the agencies in your area and what they do.
- Learn who the people are who are well regarded and seek their counsel.
- Offer your energy and talents in a substantive way - write letters, talk to people who can help, support the other agencies.
- Involve other agencies in planning and development.
- Begin by filling in the most glaring gaps.

This last point is an important one. There is not one agency providing services for disabled people that does not have a good idea of what is needed locally. It's not at all remarkable that these perceptions are shared by almost everyone. Creating an after-school program when three other agencies provide some sort of recreation won't get them on your side. But creating, say, an in-home respite care service for handicapped children might very well.

Where do we plan to go from here? There are a few things that won't change. We plan to limit our services to the geographic area we now cover. We feel strongly that programs that range all over the map tend to become administratively oriented. Decisions tend to be made for agency reasons rather than client reasons. This militates against effectiveness of service.

But when we said earlier that what we offer is still not enough, we expressed an obvious fact that has less than obvious solutions. Parents - especially working parents - have a great need for after-school programs. During school vacations and holidays there are few programs available. In the summer months - especially for multihandicapped children - there are insufficient summer programs. And for parents who need their home to themselves, there are not enough respite facilities providing out-of-home services.

Percolating in the backs of our minds are some services to fill these gaps. We hope to be able to set up small respite facilities and a summer camp some day, and we have some preliminary plans made. Working with other groups,

we hope to set up after-school programs and a recreation facility for handicapped youngsters. Discussions are in progress with the respite providers at our monthly meetings to plan and design such a respite center that will provide drop-in facilities for parents with their children as well as providing care for children without their parents present.

We see a need for providing a social environment for parents where they can find other parents who share their dilemmas and problems without forcing them into parent groups that tend to be ponderous as time goes by. This last point is an important one. Many parents complain that they are repeatedly offered parent groups for discussing the psychological impact of having a disabled child. In the early years these groups are valuable, but eight to ten years into being special needs parents, it all begins to get a little tiring. They've faced the problem long ago. Now they want to share their experiences on a less formal level and in an atmosphere more socially oriented. The respite center would help to provide that.

We're proud of what we have done. We're excited about where we are going. We're also convinced that any group of parents and professionals can accomplish the same thing. It is tempting to think globally. If you have a good idea it is hard not to think in terms of expanding it to include all the neighboring communities - eventually perhaps, the state. Then - who knows? The country? But we feel that staying small, staying local, will provide the finest services. Each locality has different needs and different solutions will be needed in each. The most effective way of meeting those needs is by limiting services to a geographic area while expanding the services to fill the needs of that area.